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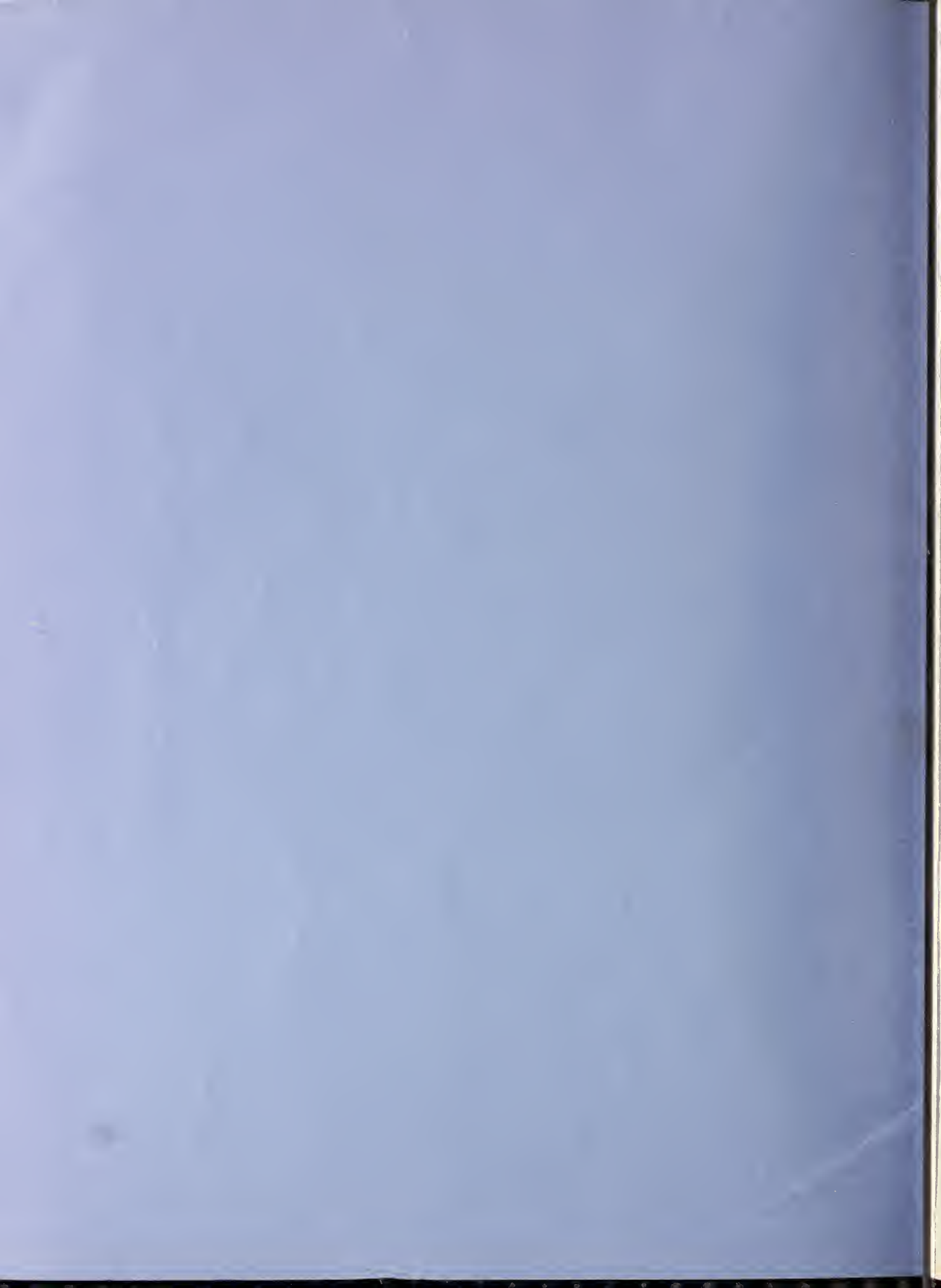
# HEW SECRETARY'S TASK FORCE ON HOSPICE

DECEMBER 1978



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Office of the Secretary  
U.S. DEPARTMENT OF  
HEALTH, EDUCATION, AND WELFARE



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ON

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U. S. DEPARTMENT OF

HEALTH, EDUCATION, AND WELFARE





DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
THE OFFICE OF THE SECRETARY  
WASHINGTON, D.C. 20201

THE GENERAL COUNSEL

December 19, 1978

TO THE SECRETARY

Attached is the report of the Hospice Task Force drafted in response to your memorandum of May 29, 1978. The Task Force examined the current status of the hospice movement in this country, the effect of current policies, statutes and regulations on hospices, and explored the various roles which the federal government might play in its development.

I want to express my appreciation to the Task Force members not only for their hard work but also for their personal commitment to finding a more compassionate way of caring for the dying.

F. Peter Libassi  
Chairman of Hospice Task Force

Attachment





DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
OFFICE OF THE SECRETARY  
WASHINGTON, D. C. 20201

May 29, 1978

MEMORANDUM TO: General Counsel  
Administrator, Health Care Financing Administration  
Assistant Secretary for Health  
Director, National Institutes for Health  
Director, National Cancer Institute  
Assistant Secretary for Planning and Evaluation

SUBJECT: Hospice Task Force

Hospice is a program of care which provides comfort (symptom control), social, psychological and spiritual support and multi-disciplinary health-related services for patients in the terminal stage of illness, and their families.

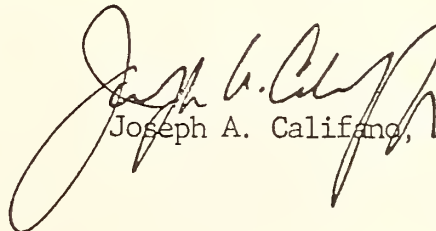
I have asked Peter Libassi, General Counsel, to chair a Task Force to study hospice; Laura Miller will be my representative on this group.

The Task Force should:

- o examine current activities (both within and outside the Department) which relate to hospice;
- o explore and make recommendations on the appropriate Federal role in hospice. This study should include an analysis of possible statutory and regulatory changes.

The Task Force should submit a proposed work plan by June 16 and report back to me with findings no later than August 1, 1978.

Mr. Libassi or Ms. Miller will contact you within a week regarding the first meeting of the Task Force.

  
Joseph A. Califano, Jr.

cc: Ms. Laura Miller



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## TABLE OF CONTENTS

I. Introduction	pg. 1
II. Background of Hospice Concept	pg. 1
A. History	pg. 3
B. Types of Hospices	pg. 4
1. Freestanding With No Hospital Affiliation	pg. 4
2. Freestanding Hospice with a Hospital Affiliation	pg. 6
3. Special Hospice Unit Within a Hospital	pg. 7
4. Hospice Team Operating Within a Hospital	pg. 8
5. Home Care Only	pg. 9
C. Criteria for Admission to Hospice	pg. 10
1. Nature of disease	pg. 10
2. Life expectancy	pg. 10
3. Geographic Limitations	pg. 10
4. Involvement of a Personal Physician	pg. 10
5. Involvement of a responsible relative or friend	pg. 10
D. Health Manpower Used	pg. 11
E. Operational Problems	pg. 12
1. Physician attitudes	pg. 12
2. Continuation of Active Treatment	pg. 13
3. Financing of Hospice Care	pg. 13

F. Special Problems of the Terminally Ill	pg. 13
1. General	pg. 13
2. Symptom Control	pg. 14
3. Control of the Environment	pg. 16
4. Consistent Emotional Support for the patient and the family	pg. 17
5. Staff Support	pg. 18
G. Current HEW Activities	pg. 18
1. National Cancer Institute	pg. 18
2. Health Care Financing Administration	pg. 19
3. National Institute on Aging	pg. 20
4. Office of Human Development Services/Administration on Aging	pg. 20
5. Ad Hoc Interagency Committee on New Therapies for Pain and Discomfort	pg. 20
6. Bureau of Medical Services, Health Services Administration	pg. 21
7. Health Resources Administration	pg. 21
H. Private Insurers	pg. 22
I. Hospice Effectiveness	pg. 22
III Department Response	pg. 27
A. General	pg. 27
B. Health Planning	pg. 28
C. Direct Operational Support	pg. 31
1. Integration into existing health delivery systems	pg. 31
(a) Community Health Services	pg. 32

(b) Home Health Program	pg. 34
(c) Health Maintenance Organization	pg. 35
(d) The National Health Service Corps	pg. 36
2. Financial Support for Construction	pg. 36
3. Financial Support for Training	pg. 37
D. Reimbursement	pg. 40
1. General	pg. 40
2. Beneficiaries	pg. 40
(a) Medicare	pg. 40
(b) Medicaid	pg. 42
3. Benefits	pg. 44
4. Providers	pg. 49
(a) Medicare	pg. 49
(b) Medicaid	pg. 50
5. Demonstration Authorities	pg. 51
E. Non-financial Assistance	pg. 53
IV. Other Federal Activities	pg. 55
V. Quality Control	pg. 56
1. Standards for Hospice Programs	pg. 56
2. Utilization Review	pg. 59
3. Fraud and Abuse	pg. 59



## REPORT OF THE HOSPICE TASK FORCE

### I. Introduction

This Report has been drafted in response to your memorandum of May 29, 1978 directing that a Hospice Task Force examine the current status of the hospice movement in this country, the effect of current policies, statutes and regulations on hospices and explore appropriate roles which the Federal government might play in its development.

To accomplish this, a Task Force was convened including representatives of those Offices in the Department whose functions relate to hospice activities. Each Office was asked to survey, analyze, and report on a particular aspect of "hospice." To a great extent this report is based upon those responses as well as numerous contacts with persons outside the Department who have been active in the hospice movement.

### II. Background of the Hospice Concept

The growing interest among Americans in death has led to increased concern with the manner in which people who are considered terminally ill spend their final weeks or months. There has been particular concern about individuals with terminal cancer, both because of the nature of the disease and the number of deaths involved. The American Cancer Society estimates that during 1978, 390,000 Americans will die of cancer--one every 80 seconds, and that one in four Americans now living--55 million Americans--will eventually have cancer. 1/ Further, the American Cancer Society estimates that in the 1970's there will be 3.5 million cancer deaths, 6.5 million new cancer cases, and more than 10 million people in the United States under medical care for cancer. 2/

At the present time most terminal care (almost 70%) occurs in general hospitals, nursing homes or other facilities,

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1/ 1978 Cancer Facts and Figures, American Cancer Society, Inc., New York, 1977.

2/ Ibid.

despite evidence of a growing interest in dying at home. 3/ In 1976, 1.2 - 1.5 million people were expected to be hospitalized as cancer patients at an anticipated cost of \$3.5 billion. 4/ However, the factors that combine appropriately to form the normal process of acute care in hospitals may not only be inappropriate and excessively costly, but even counter-productive when the patient is dying. The needs of the dying patient for comfort, concern, family, friends, and freedom from pain, together with dissatisfaction over the high cost of dying, have led to the exploration of alternative approaches to providing care for the terminally ill. 5/

The alternative currently receiving the closest scrutiny is "hospice," a concept of care and services which provides palliative and supportive care for terminally ill patients and their families. The hospice concept of care emphasizes symptom control, strong patient and family support including preparation of death, and home care instead of institutionalization when that choice is feasible. One basic precept which underlies the concept is that caring is more important than curing once the chance for curing is considered past. Services are provided by an organized multidisciplinary team which is available on a 24 hours-a-day, 7 day-a-week basis. The patient and his or her family is seen as the unit of care. Care of the surviving family members continues after death in order to provide assistance in the emotional, social and physical adjustment to loss and is called "bereavement services." The goals of hospice care have been stated as:

- Keep patients at home as long as possible.
- Make patients as symptom free as possible.

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3/ Nelson, R.J. "Hospice: An alternative Solution to the Problem of Caring for the Dying Patient." Cited in Ryder, C. and Ross, D.M., "Terminal Care--Issues and Alternative," Public Health Reports, Vol. 92, No. 1, January - February 1977, p. 22.

4/ Scotto, Joseph, M.S., and Chizze, Leonard, Jr., SCD, "Cancer Prevalence and Hospital Payments," J. Nat'l Cancer Institute, Vol. 59, No. 2, August 1977, p. 345-349.

5/ A 1973 study by Cancer Cure, Inc. indicated that the median cost incurred by families of cancer patients was \$19,055, or more than twice the median family income of \$8,000. Cited in Ryder, C. and Ross, D.M., p. 20.

--Support the family as the unit of care and encourage both the patient and the family to participate actively to the extent possible in the provision of care.

--Allow the patients to live as fully as possible until death.

--Reduce the cost of caring for the terminally ill. 5a/

#### A. History

The term "hospice" is derived from the Latin for "host," "guest" or "stranger," and "hospitum," which means "welcome reception for strangers." Hospices developed in Italy, England, France, and Germany during the Middle Ages. They usually were run by monastic orders and were the places where early "medicine" was practiced. They were not particularly concerned with care of the dying, but with care for all who came, particularly the indigent.

The first modern hospice devoted to the care of the dying was established by the Irish Sisters of Charity in Dublin during the middle of the 19th century. The early European hospices combined good nursing care, spiritual and emotional support, and home care, but the development of theories of control of pain associated with terminal cancer, and the sophisticated management of other symptoms, are attributed to Dr. Cicely Saunders, a British nurse and physician. The hospice which she directs, St. Christopher's, founded in one of 25 hospices now operating in Great Britain, is regarded as a model by many hospice supporters in this country.

The hospice movement in the United States is young and small, but expanding rapidly. As of July 20 we have identified 36 programs in 16 States and the District of Columbia that are currently serving patients; the oldest of these (in New Haven, Connecticut) began with a home care program in 1973. In addition, we have identified 16 other groups that are either developing a patient care program or that are serving as a facilitating/coordinating organization for others. Both of these numbers undoubtedly understate the level of

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5a/ Lack, S.A., "The Hospice Concept--The Adult With Advanced Cancer." American Cancer Society's Second National Conference on Human Values and Cancer, Chicago, Illinois, Sept. 7-9, 1977.

activity nationally. 6/ The National Hospice Organization, Inc. is presently undertaking a survey of hospice activity which should provide a better count of activities nationwide.

Sponsorship of American hospices vary widely. Many of the programs we have identified are hospital based, but there are a number which are independent corporate entities. While there appears to be little formal sponsorship by churches, virtually all programs have a spiritual dimension and most include clergy on either the paid or volunteer staff. The Catholic Hospital Association has, for example, taken a leadership role in educating its membership on the hospice concept. Three meetings on hospice care are going to be conducted by the Association this Fall. Further, church organizations and individual members of the clergy have been instrumental in developing hospices under other sponsorship. Nursing nuns initiated some of the European hospices, as noted above, and still operate several hospitals for the terminally ill (e.g. Calvary Hospital in the Bronx, N.Y.)

Our initial information (based on the literature, telephone calls and several site visits conducted by the Health Resources Administration) suggests that American hospices fall into five types, or models: (A) freestanding hospices; (B) freestanding hospices with a hospital affiliation; (C) hospice units within a hospital; (D) hospice teams within a hospital; and (E) home care only.

## B. Types of Hospices

1. Freestanding Hospices With No Hospital Affiliation. We are aware of two freestanding autonomous hospice organizations operating or soon to be operating: Hillhaven Hospice in Tucson, Arizona, and Hospice, Inc. in New Haven/Branford, Connecticut. Because of the major difference in clinical emphasis (palliative rather than curative medicine) and a desire to maintain a warm, inviting environment, some hospice groups wish to operate outside of and unattached to a hospital. However, groups that have an inpatient facility use it as

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6/ This survey was prepared by the Office of Planning, Evaluation, and Legislation, Health Resources Administration.

backup for patients who cannot be cared for satisfactorily at home; 7/ typically inpatient stays last only a few days or weeks and occur just before death. There have been two major concerns expressed with the establishment of freestanding inpatient facilities. The first concern is that with its own inpatient facility, a hospice may reduce its emphasis on home care which is recognized by most as a mainstay of the hospice concept. The second concern expressed is that use of such facilities make institution or reinstitution of medical treatment difficult and unnecessarily create a situation in which hospice care and medical treatment are mutually exclusive.

Hillhaven is sponsored by the Hillhaven Foundation of Tacoma, Washington. The 39-bed hospice opened in April, 1977. There are 20 full-time nurses on the staff; patients retain their own personal physicians. In addition to inpatient care, Hillhaven offers home care, day care, and a 12 month bereavement support service for the family. Home care services are provided by an arrangement with the Tucson Visiting Nurses Association (VNA) during normal working hours. These services are supplemented by the hospice staff during evenings and weekends. Hillhaven is one of three programs selected by the National Cancer Institute to participate in an evaluation of hospice care.

Hospice, Inc. New Haven, began with a home care program in 1973 after years of organization by persons who had worked at or visited St. Christopher's. The home care program began with donations and an approximately \$775,000 three year contract with the National Cancer Institute for delivery of services by a multidisciplinary health

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7/ Hospice inpatient facilities may become necessary when (1) there is no one in the patient's home to assist the patient, (2) the patient's pain and symptoms must be closely monitored in order to be controlled, and (3) the family needs rest from the tedium and stress associated in caring for the patient.

care team to selected cancer patients in the New Haven area who were too ill for aggressive rehabilitation. Care was available on a round-the-clock basis. Approximately 414 patients and families were served during the three year funding with approximately 2/3 of these patients dying at home. Construction of a 44-bed inpatient facility, to be financed partly with Hill-Burton funds, will be completed next year.

Since the program began, it has averaged a caseload of 30-35 patients at any one time and a bereavement followup caseload of about the same number. Average length of stay in the home care program for the terminally ill patients cared for in the hospice's first three years was 3.1 months, during which there was an average of two physician home visits, 12 nurse visits, and two visits by social workers and other team members. 8/ The average cost per home visit was about \$28.00. 9/ The Administrator estimated that \$750 would cover the total cost of home care for the average patient. Further, Hospice, Inc. New Haven projects that costs at its inpatient facility when completed will be a little less than \$100 a day (with an estimated 10 day length of stay), compared to an estimated \$190 a day for a general hospital in that geographic area.

2. Freestanding Hospice Program With a Hospital Affiliation. The Riverside Hospice program in Boonton, New Jersey differs from Hillhaven and Hospice, Inc. in that it is a freestanding hospice facility with a hospital affiliation. It is, in fact, a division of Riverside Hospital. For tax and financial reasons the hospice was set up as a hospital affiliate but it is "physically, managerially, and financially distinct." 10/

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8/ Plant, Janet, "Finding a Home for Hospice Care in the United States," Hospitals, Vol. 51, July 1977, p. 53-62.

9/ Charles, Eleanor, "A Hospice for the Terminally Ill", The New York Times, March 13, 1977.

10/ Plant, p. 61.

On January 1, 1977, a home care program began serving terminally ill patients 24 hours a day. This program receives funds under the New Jersey State Division of Alternative Health Systems. The home care program uses volunteers extensively, as well as the local Visiting Nurses Association; each patient's personal physician participates in the case as long as the patient wishes and the physician agrees. Charges for services are determined by a social worker on the basis of a sliding scale.

The in-patient component is housed in a leased private home accommodating 16 patients. It has a certificate of need from New Jersey and has been working with the State in meeting fire and other safety and health code requirements. Riverside receives support for its current operations under a demonstration grant from the National Cancer Institute.

3. Special Hospice Unit Within a Hospital.  
Setting aside a special unit for hospice care within a hospital is getting increasing attention partly because this arrangement may avoid problems of reimbursement since the special unit obtains reimbursement on the same basis as other services in the hospital. Such an arrangement also lessens the difficulties in obtaining certificates of need since health systems agencies and State agencies are familiar with hospital based services. The prototype for this model is the 12-bed Palliative Care Unit within the Royal Victoria Hospital in Montreal, Canada. A 10-bed unit modeled after the Palliative Care Unit was opened in July, 1977 at the Bellin Memorial Hospital in Green Bay, Wisconsin. The 245-bed hospital is nominally affiliated with the Methodist Church.

The hospice unit is administered under the chaplaincy department of the hospital. The Carl Kouba Hospice at Bellin Memorial has a full-time director who is a physician; other regular staff include nurses, aides, and 25 volunteers. The hospital chaplain and ancillary hospital staff (social worker and physical and occupational therapists) participate as needed in patient care. The hospital operates its own home care program which

serves the hospice patients; supplemental services are provided through the local VNA. There is a strong emphasis on relationships with the families of patients; the hospice includes an attractive lounge where patients and families may gather and a "transition room" where patients are taken immediately after death and where families are encouraged to spend as much time as they wish.

The Carl Kouba Hospice has had 87 inpatients and 23 home care patients (only one of whom is not included in the 87). The average inpatient length of stay is 9 days; the mean home care period is 48 days. The average inpatient charge is \$163 per day; most patients have coverage under Medicaid, Medicare, or other insurance. Home care is reimbursed at \$35 per visit which doesn't cover current costs, but the director projects that it will as the home care volume increases.

One of the major obstacles to adoption of this model of hospice care however is the ability to ensure the requisite autonomy within an established health care facility that is essential to implementing fully the hospice concept, since such facilities have many established practices (visiting hours, personnel practices, health regulations) contrary to the hospice philosophy. At the same time this model does prevent the fragmentation of services provided to the patient and previous health care givers remain available for continuity of care.

4. Hospice Team Operating Within a Hospital.  
At St. Luke's Hospital in New York, a multidisciplinary hospice team--three part-time and one full-time nurse, one psychiatrist (1/8 time), a medical director (1/2 time), a chaplain (1/2 time), a social worker (4/5 time), and two volunteers--visits dying patients throughout the 776-bed general hospital, in addition to operating a home care program. Since the program began in April, 1975, the team has served about 280 patients and their families; the average is eight at any one time.

The hospice coordinator believes the presence of the hospice team has had a beneficial effect on the way the hospital operates and on the way the staff in general approach terminal patients. It also reduces the isolation of the dying patients and allows for integration of all services provided the patient. St. Luke's does not plan to create a specialized hospice unit within the hospital for fear of jeopardizing its current reimbursement status as an acute care facility and because of a conviction that a single unit would not be helpful to their heterogeneous patient population (an estimated 50 percent are Hispanic, black or Caribbean).

5. Home Care Only. Hospices with no central facility as backup, sometimes called "hospices without walls," are typified by the Hospice of Marin (Kentfield, California), founded in 1976 by a physician. Its team of health professionals offers four types of services: management of the patient's pain and related symptoms, instruction of family members in care of the patient, consultation with and emotional assistance to the family, and bereavement support for survivors. The patient/family chooses one or more services, total hospice care includes all four. From September 1976 to October, 1977, 29 persons were admitted to the program and there were 19 deaths -- all at home. The average patient/family case load carried by the hospice of Marin at any one time is 21-22.  
11/

All of the funds for this hospice have come from private sources such as foundations, the American Cancer Society, individual contributions and donations from friends and families of patients. Hospice of Marin has the active support of the Marin Medical Society; most of its patients come from physician referrals. 12/

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11/ Hospice of Marin, News, Vol. II, No. 77 October-November 1977.

12/ Lewis, Toney, "Hospice of Marin: Caring for the Terminally Ill at Home," Twin Cities Times, March 29, 1977.

C. Criteria for Admission to Hospices

While admission criteria for admission of patients to hospices differ across programs, they usually include;

1. Nature of disease. The majority of patients have cancer, and in some cases admission is restricted to these patients. It appears that even where people with any terminal illness are eligible, most admissions tend to be for cancer. Hospices normally admit severely symptomatic patients who are not amenable to curative disease treatment and are not responding to disease palliation.
2. Life expectancy. Patients must have an expectancy of weeks or months; sometimes a specific period (usually six months or less) is indicated. However, it is recognized that in any case this is a matter of medical judgment since there is no specific test that determines life expectancy for any specific disease category.
3. Geographic limitations. Sometimes residence in a particular county is required. In other cases, a particular radius around the project is specified in order to assure close family involvement.
4. Involvement of a personal physician. Nearly all programs require that the patient's own physician continue to direct the care. Some require the referring physician agree to make house calls for home care patients at any time around the clock in order to assist in providing continuity of care.
5. Involvement of a responsible relative or friend. Most hospices require a specific person to serve as the primary contact and to assume ongoing responsibility for care in the home. Where the family is fragmented or there is no substitute, patients will not usually be accepted, especially for a program that offers only home care.

D. Health manpower Used

As discussed previously, an integral part of the hospice program of care is the involvement of a multidisciplinary team in providing care, as needed, 24 hours a day, seven days a week. Although the composition of the team (which may be paid staff or volunteers) varies, the teams are usually composed of: physicians, psychiatrists and psychologists, nurses (registered nurses, visiting nurses), licensed practical nurses, nurses aides, social workers, home health aids, chaplains, and volunteers.

The hospice movement stresses the team concept so that at any time in the plan of care for a patient and family any individual on the team may surface as the team leader depending upon patient needs at that point in time. Despite local variations however, it appears that although the physician member of the team remains primarily responsible for continuing medical care, the nurses and volunteers (who may themselves be highly trained and experienced nurses) assume major responsibility for care, especially in hospice programs of care with a strong home care component. The staffing patterns however appear to differ depending upon the setting, community and financial resources, population groups served models of hospice care and objectives of the local program. There is at this time no firm basis for determining what the "appropriate" hospice staffing pattern should be.

With respect to the training of hospice staff, both paid and volunteer, professional and nonprofessional, each active hospice appears to have developed an individualized training programs which vary from a few hours a week for several months for volunteers, to an intensive 5 day seminar for staff. This training appears to focus upon (1) developing an understanding of the hospice concept of care, (2) developing coping mechanisms in working with the terminally ill and their families, (3) learning to deal with the emotional impact of death, (4) learning about community resources relating to the care of the individual and the family, and (5) learning to participate in a true multidisciplinary team approach to the provision of care.

The role of volunteers in the hospice movement has been critical. Some programs (e.g., Hospice of Santa Barbara,

Shanti Project in Berkeley, Elisabeth Kubler-Ross Hospice in Clearwater, Hospice of Maine in Portland) are staffed entirely or primarily by volunteers who may themselves be health professionals. Where programs don't list physicians among the paid staff, they are using volunteer physicians, or rely mainly or exclusively on each patient's personal physician (e.g., Methodist Hospital of Indiana, Inc.; Carl Kouba Hospice in Green Bay, Wisconsin). Clearly the volunteers play diverse roles depending upon their skills and prior experience. Some talk with patients, assist with routine patient care, or run errands for patients. Others staff the hospice office, render professional care as physicians, nurses, or clergy, or make funeral arrangements. Volunteers often provide bereavement follow-up services, freeing the paid staff to support the needs of current patients.

#### E. Operational Problems

In the preparation of this report, individuals to whom we have spoken who are actively involved in hospice have identified the following as significant problems:

1. Physician attitudes. Many physicians are reluctant to seek hospice care at all for their patients who could benefit, or to seek this care soon enough to permit the staff to help significantly. This seems to stem, at least in part, from the physicians orientation toward curative therapy rather than palliative care. Physicians question whether patients will be deprived of curative treatment by premature referral to a hospice. By training and tradition, physicians as well as other medical professionals are dedicated to the maintenance of life and look upon the death of a patient as a defeat. Further they have had little formal training to guide them in administering to the dying and their family. A recent survey of 107 U.S. medical schools prepared by the Foundation of Thanatology showed that only seven had a full time course in thanatology. Some California programs suggest that physicians can become hospice supporters by seeing a "successful" case (one in which the patient dies comfortably and the family is satisfied with the experience). Staff and directors of in-hospital hospices generally believe their practices are having a positive influence on the behavior of physicians and nurses in the other departments.

2. Continuation of active treatment. While some programs follow the "English rule" that no patient still on active treatment should be admitted for hospice care, several hospice leaders believe strongly that American physicians, particularly oncologists, will not support hospices unless they are allowed to admit patients for whom they and the family wish to continue active therapy until the time of death. Physicians are concerned that hospice care will be viewed as a "one-way ticket" -- they feel that the opportunity for disease oriented therapy should continue to exist. This issue is controversial and has yet to be resolved within the hospice community. One Midwestern program has dealt with this issue by permitting such admissions but requiring the primary physician to include only patients with very short life expectancies.

3. Financing of hospice care. The innovative nature of hospice care, carried out many times outside traditional health care facilities, with its emphasis on palliative rather than curative care, its emphasis on the family as the unit of care, and its use of a complex variety of multidisciplinary skills that vary over time in frequency, duration and intensity (including skilled medical services provided by physicians, nurses and therapists, social services and, nutritional and personal care services), has created for many hospices serious reimbursement problems. This will be discussed in detail later in this Report.

F. Special Problems of the Terminally Ill.

1. General. Whether "hospice" is regarded as a wholly new concept or simply a logical but more comprehensive and humane application of the present methods of caring for the terminally ill, is irrelevant. As discussed earlier, the fact remains that health care professionals and the public at large are increasingly questioning the appropriateness of current means for caring for the terminally ill and becoming increasingly concerned with the need to develop more appropriate modes of care. For example, the hospital is an acute care facility the institutional purposes of which are to investigate, diagnose, and cure disease and prolong life. As such, the thrust of

the entire operation is not geared to the palliative care of the terminally ill. Routine medical care procedures, visiting hours, meals, and even the physical environment itself are all designed to facilitate rehabilitative care for the acutely ill patient. The terminally ill patient, for whom rehabilitation is no longer helpful, is an anomaly in this environment. The focus on the illness and not the person, becomes inappropriate. The hospital may not be capable--by virtue of its very nature--of meeting the needs of this type of patient.

In addition to the institution's orientation and design, the professionals who provide care in the hospital are, by training, often not prepared to cope with the needs of the dying patient. Their professional orientation and training stresses the saving of lives; the loss of a patient is often viewed as a professional "failure". The medical care professionals, despite their exposure to sickness, generally are not prepared in their training to cope with the experience of a patient's death. As a result, the medical care professional is often uncomfortable discussing impending death frankly with a patient or patient's family. This inability to confront a patient's death promotes both inconclusive interaction and destructive practices in the actual hospital situation.

The needs of the dying patient which do not seem to be ~~be~~ properly met in the acute care environment as discussed in detail below include symptom control (e.g., insomnia, incontinence, anorexia) retention of control over the immediate environment, and consistent emotional support for the patient and the family. Finally, the staff working with the dying need assistance and support in their efforts so that they can more effectively help the patient who is dependent on them for care.

2. Symptom Control. The cancer patient who is dying may suffer from a variety of symptoms of his or her disease, including breathlessness, anorexia, weakness, depression, lethargy, constipation, vomiting and incontinence. The most prominent of

these symptoms is chronic pain. Although only perhaps 40% of cancer patients develop the intense chronic pain associated in the popular consciousness with cancer, this symptom is a devastating one for those who experience it, and it is the most dramatic and well-known symptom of cancer. Whether or not an individual experiences this pain, the other symptoms noted above are capable of seriously interfering with the quality of his or her remaining life.

Standard medical practice is to allow pain to develop before providing relief; pain medication is not used to control pain, but to subdue it after it emerges. The specific practice involves the physician's order for pain medication "as needed," which means that nursing staff will supply the medication when the patient asks for it. The patient, then, must experience pain before relief is offered.

Two facets of the terminal patient's pain experience which make this practice even more inappropriate are the intensification of pain due to anxiety and the emotional significance of the pain to the patient. For the patient, whose pain can be enduring and excruciating, the expectation of pain can cause great anxiety. The patient's high level of anxiety -- the fear of devastating and inevitable pain -- can make the subjective experience of that pain even more intense. Furthermore, chronic pain is a constant reminder of impending death.

The hospice concept on the other hand has as one of its goals the maintenance of the patient as pain free as possible, and therefore a treatment regimen is adopted which prevents pain rather than focusing only on controlling it once it is present.

A final aspect of acute care pain relief practice which seems inappropriate to the terminally ill patient so long as there is no reason to believe that partial or total recovery including remission can occur is the limitations on the choice of pain medication. Generally, health care providers are hesitant to use narcotic agents to control pain

because they fear patient addiction and are concerned about reaching a dosage level which will prove ineffective. Narcotics, however, have been shown to control pain in advanced cancer patients more effectively than other drugs. Given the imminence of death, addiction does not ordinarily present a significant problem. 13/ The use of narcotics does not seem to present a problem in terms of tolerance, either. There seems to be a self-limiting process at work in which, while dosages must be increased over an initial period, they can gradually be decreased to a plateau. 14/

In the past, the combination of drugs favored by the hospice movement in Great Britain has been a "Brompton cocktail" made up of heroin, cocaine, gin, sugar, syrup and clorpromaxine syrup. Many hospices (including St. Christopher), however, are now switching to a "mix" excluding the cocaine and substituting morphine for heroin and have found it, except in rare cases, an equally effective treatment given orally and corrected for dosage amount. Heroin by injection does appear to be preferred however in 10% or less of hospice cases where during the last few days of life patients are unable to take liquids.

3. Control of the Environment. The traditional modes of care or treatment do not seem to meet a second major need of the dying patient, that of control over his or her personal living environment. The loss of control over daily activities, physical environment, etc., can add to the fear and sense of helplessness the dying patient feels.

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13/ Nevertheless, somewhat of a dilemma is presented. The conscientious physician does not want to be fortunate enough to produce a significant remission, only to find him or herself treating an addict.

14/ The issue of the most appropriate and efficacious drugs, or combinations of drugs for pain relief is beyond the scope of this Task Force. These issues are being fully explored by the subcommittee on the terminally ill of the Interagency Committee on New Therapies for Pain and Discomfort.

Unfortunately, the acute care setting does not in most cases today promote or allow for this type of freedom in controlling daily activities. As noted above, the hospital's treatment orientation involved schedules, visiting restrictions, a sterile environment, institutional food, and other characteristics of care structured for short term stays. This setting promotes the patient's feelings of helplessness rather than counteracting them.

The hospice concept, on the other hand, focuses on allowing patient flexibility to the extent possible. This is true whether services are being delivered at home or in a hospice facility. In the facility, arrangements are made for flexible visitation hours by all members of the family, for individualized menus, and for the furnishing of rooms with personal items that create a homelike environment. Because there is no need for the facility to maintain elaborate medical support mechanisms, flexibility may be more easily achieved.

4. Consistent Emotional Support for the Patient and the Family. A third need of the dying patient is for emotional support from family, friends and staff. Unfortunately, under traditional modes of care the patient often suffers from feelings of isolation and loneliness. Staff members in institutions often are personally uncomfortable with the dying patient and give priority to patients who will recover. The result is that the patient tends to be ignored by staff, in terms of both prompt and effective symptom relief and simple human contact. Too often the terminal patient is physically moved to the far end of a ward or some other isolated place, separated from other patients and from staff. The family of the terminally ill patient may need help in coping with immediate types of problems, such as how to discuss impending death with their loved one or how they can help to make him or her feel more comfortable. They need help in coping with their own feelings about death and about their loved one's death. The family needs encouragement and assistance in planning in practical terms for the future without their loved one. The bereavement period following the death of the patient is stressful. Studies indicate that morbidity and mortality among bereaved spouses is unusually high in the first 12

months following the death of a loved one (Royal Victoria Hospital, 1976). Provision of emotional support to family members during this period could ameliorate the destructive impact of their loss.

Although there is a substantial need for family support, hospitals are not set up to provide this support in the quantity or quality required. Families are left to cope with this experience alone. They do not receive the formal and informal interaction they need with the staff.

As indicated previously, in the hospice concept the family is the unit of care. The family remains involved in the care giving process and participates in decisions relating to such care. In many programs the family maintains an involvement with hospice personnel after the patient dies. The hospice, through its multidisciplinary team, provides supportive services to the family to assist them in handling both the emotional and practical effects of impending death.

5. Staff Support. As noted above, health care providers often are not prepared to cope with their own feelings about death or with the reality of a dying patient. Psychiatric consultations, supportive interaction with other staff and with patients, are necessary to enable staff to approach the dying experience more appropriately. Staff need preparation and ongoing support in order to deal adequately with their personal stresses so that the provision of care that the patient and his/her family desperately need is not jeopardized.

#### G. Current HEW Activities

While the Task Force report represents the first coordinated attempt, Department-wide, to begin to surface the myriad of issues raised by the hospice movement, there are a number of activities which have or are being undertaken around these issues by different segments of the Department:

1. National Cancer Institute. In 1974 the National Cancer Institute awarded a three year demonstration contract (September 3, 1974 - September 2, 1977) to Hospice Inc. of New Haven

in the total amount of \$771,292 to develop and implement on a demonstration basis a plan of continuing care, on an "at home basis" for cancer patients whose disease could not be cured or controlled. In addition, the National Cancer Institute recently awarded three year contracts to Riverside Hospice in New Jersey (\$1,511,421) Hillhaven Hospice in Arizona (\$1,700,718) and Kaiser Permanente Hospice in Los Angeles (\$1,645,373) to provide for a limited demonstration program to field test the St. Christopher's hospice concept of care of the terminal cancer patient. Each of the participating hospice programs is a freestanding hospice that operates a relatively large home care program and a small in-patient facility. A major part of these demonstration projects is a rigorous collaborative evaluation to test the effectiveness and applicability of the hospice concept in this country.

The National Cancer Institute is also considering funding some investigator--initiated grant proposals to demonstrate new concepts and procedures for the improved care of patients with terminal stage disease.

2. Health Care Financing Administration. The Health Care Financing Administration has issued an invitation to conduct multiple medicare and medicaid demonstrations with hospices in various settings. Hospices which have only a home care program and hospices with a combined inpatient/home care program will be eligible to respond, as well as hospices which are freestanding providers, or affiliated with a hospital, skilled nursing facilities or other providers. While the demonstration projects will waive some Title XVIII and XIX coverage requirements, and allow for reimbursement of otherwise non-covered services, there will be no funds available to establish or administer the hospice other than the normal services reimbursement.

The objectives of these demonstrations are (1) to identify the levels of care provided by hospices in a home and in-patient setting; (2) to evaluate hospice services in various settings as an alternative service and delivery system for the care of

the terminally ill; (3) to evaluate the cost of hospice services; (4) to evaluate the comparative costs of hospice services provided in the home and in-patient settings, and (5) to devise appropriate certification standards and reimbursement methods, and to recommend the proper role, function, and mechanics of utilization review and PSRO mechanisms. Although final evaluations of these projects is not to be completed until 1981, interim reports will be submitted on a periodic basis.

3. National Institute on Aging. Although the National Institute on Aging has no statutory authority to support hospice activities per se, in a broader context it does support several projects dealing with the psychological and social implications of bereavement, widowhood and death or dying. In addition, the Institute is funding projects in the area of pharmacology and aging, with special emphasis on the role of age in pharmacokinetics and pharmacodynamics, which will contribute to the understanding of pain management in terminal illness of the elderly.

4. Office of Human Development Services/Administration on Aging. The Office of Human Development Services is in the midst of reviewing grant applications for funds under the Model Projects on Aging Program authorized by Title III, Section 308 of the Older Americans Act of 1965, as amended. The program announcement indicates that proposals to adapt and incorporate the hospice concept in the aging services system with attention to receptiveness to such a service by older persons, the level and type of professional preparation and support required, and alternative organizational arrangements for the hospice within the system will be given special consideration. This type of project is one of three projects under the category of "community care services": for which \$900,000 tentatively has been allotted for approximately 9-12 awards to cover all three types of projects.

5. Interagency Committee on New Therapies for Pain and Discomfort. Under the chairmanship of Dr. Seymour Perry, this Committee is charged with investigating all aspects of pain and pain control and determining an appropriate research agenda. One of the three subcommittees is exploring the needs of patients with terminal illness.

6. Bureau of Medical Services, Health Services Administration. The Staten Island Public Health Service Hospital has established a Comprehensive Cancer Support Program encompassing many of the hospice concepts. This program has three primary focuses: (1) a patient cancer support group in which from 5 to 15 patients diagnosed as having Stage II cancer (patients with progressive disease; little chance of cure and likely to die within 5 years) meet weekly with the health care team in an attempt to help these patients (and their families) cope with the emotional and social distresses associated with the disease. Although most of the participants are outpatients, inpatients also join the meetings if able to leave the wards; (2) a cancer support unit composed of two rooms (6 beds) which has been designated for inpatients with progressive cancer. A fundraising event paid for the refurnishing of the two rooms to create a more pleasant homelike atmosphere, as well as the purchase of a special electronic device for chronic pain relief, which could not be purchased through normal hospital funding; and (3) a professional cancer support committee which includes members from various disciplines such as medicine, nursing, psychiatry, occupational therapy, social work, chaplaincy, dietetics, and health education, which meets weekly to provide time to plan specific case management and to also provide a means of coming to grips with their own feeling about their own death as well as with the patients.

This project has been very well received in the community and has just issued its first annual report which described the formation and development of the program on which approximately \$210,000 has been spent over the last year. The Bureau of Medical Services is currently evaluating the operation of the Staten Island programs.

7. Health Resources Administration. The Health Resources Administration has been surveying and analyzing the development of the hospice movement within the United States. It is currently considering funding a project to produce a "state of the

art" document describing current practices of selecting and educating practitioners (physicians, nurses, social workers, and others) to work with dying individuals; and make recommendations for improved practices.

Overall, most components of the Departments contacted which were not already engaged in hospice activities indicated a desire and interest in getting involved in such activities in the future.

#### H. Private Insurers

The insurance industry, not unlike the Department is just getting involved in reacting to the growth and potential of the hospice movement. Four local Blue Cross plans -- in New Haven, Connecticut, Rochester, N.Y., Washington, D.C. (on a pilot project basis), and Tucson, Arizona, have adopted plans which explicitly cover hospice services. In addition, at least two commercial carriers (Aetna Life and Casualty and Connecticut General Life Insurance Co.) are covering all hospice services except bereavement. In addition, home health benefits are generally available under major medical plans although there is little utilization by subscribers. Representatives of the insurance industry -- Blue Cross Association and Health Insurance Association of America -- are presently looking into the development of a policy on the comprehensive coverage of hospice services.

#### I. Hospice Effectiveness

Information on the ability of hospice programs in the U.S. to achieve their accepted goals (e.g., symptom control, emotional support, family care) is only now beginning to be gathered and analyzed. The organized hospice movement in the United States is still too young to provide definitive data, although expected evaluation efforts will focus on the appropriateness of this level of care and its cost implications.

The National Cancer Institute has awarded three contracts to Hillhaven Hospice in Tuscon, Arizona, Riverside Hospital in rural New Jersey, and Kaiser Permanente in Los Angeles, California to study the effectiveness of the "free-standing" hospice model relative to the more

"traditional" modes of care for the terminally ill patient. This is a 3-year pilot study, with a 15-month evaluation period. Data will be compiled centrally by NIH/NCI and uniform factors and controls will be applied to all three hospices studied. The Veterans Administration project at the Wadsworth Veterans Administration Center in Los Angeles, discussed later in this Report, will also provide valuable information on the relative medical effectiveness of hospice care. At the present time, New Haven's Hospice, Inc. is the only major U.S. program known to have undertaken substantial evaluation activities; the report on its home care program should become available in the near future. In the meantime, St. Christopher's in London and the Royal Victoria Palliative Care Unit in Montreal have implemented several evaluation and research projects. St. Christopher's has made available numerous objective and subjective studies and observations ranging in topic from use of specific pain regimens to descriptions of daily operations. The Palliative Care Unit (PCU) has begun to evaluate its own efforts. Although the resulting material is only preliminary, the PCU's approach is clearly having a positive impact on its patients.

Despite the tentative nature of the information from the programs in the U.S., it would appear that certain conclusions may be drawn. The experience in England, and to a more limited degree in this country, shows that hospice care can be successful in reducing pain, depression and anxiety in patients and in allowing patients to live more fully until the moment of death. Hospice patients also seem less concerned about their illness than do nonhospice patients. Patients maintain a more positive attitude towards the care they receive, and stay more active and social. Hospice family care also appears more successful in helping spouses and other family members live through the terminal and bereavement periods with less depression and anxiety.

The cost of caring within the traditional medical care system for those Americans dying of cancer and other terminal illnesses is significant. Cancer Care, Inc., in its 1973 study of Cost of Catastrophic Illness estimated that the inpatient cost for a terminally ill patient with cancer may vary from \$2000 - \$2500 a month; its current estimate is \$5500 - \$6000. When one links these figure with the fact that one out of every four Americans alive today -- 55 million Americans -- will contract cancer during his lifetime and that cancer

is the most likely disease to reach a point where treatment is no longer efficacious and prolongation of life is not possible; one can readily see the impact on the current medical care system. It must also be remembered that while to a great extent this Report focuses on cancer since most American hospices are primarily or solely involved with caring for those dying of cancer, there are other terminal illnesses which could also best be "treated" by use of the hospice concept.

Rigorous cost comparisons between models of hospice care and their various "benefit packages" or between traditional medical care and hospice care have not been conducted. It is anticipated that the 3 demonstration projects funded by the National Cancer Institute and the proposed HCFA demonstration projects will supply such data. There is anecdotal cost data however:

-- A pilot contract between Group Hospitalization, Inc. and the Washington Home which provides for reimbursement of their new hospice unit indicates costs in the range of \$130 - \$140 per patient day.

-- A Rochester Blue Cross study last year showed the average daily cost of home care for terminally ill patients was \$87.75, compared to a daily hospital rate of \$200.

-- One hospice has estimated the average cost per hospice patient (exclusive of any necessary institutionalization) to be \$750 - \$1000, including all home hospice services (15 to 20 visits per patient over a 3 month average "stay" at \$29 per visit), drug expenditures, the cost of rented medical equipment and the cost of physician services in the patient's home.

-- Hospitals' home care programs have been estimated as saving the equivalent of \$1,000,000 nationally per year as compared to the cost of hospitalization.

-- A May 1978 study by the Genesee Region Home Care Association of 25% of all cancer patients discharged within the first quarter of 1977 (33 patients) indicated that the patients surveyed spent an average of 39 days with Genesee Region Home Care services at a total cost of \$34,021 or an average of \$26.19 a day.

The physicians responsible for these patients estimate that if home health services were not available these same patients would have required an additional 582 hospital days at a total cost of approximately \$104,760.

-- Jack Lally of the Cardinal Ritter Institute of St. Louis, Missouri, a home health agency, cited the following comparative figures based on the actual cost of home care for terminally ill patients for about 4 months in contrast to what the cost would have been for varying patterns of care for that same period in 1972:

<u>Source of care</u>	<u>Cost</u>
Home	\$ 94,000
Hospital	\$ 1,768,000
Nursing Home	\$ 350,000
Home Care and last 2 weeks in hospital	\$ 162,000

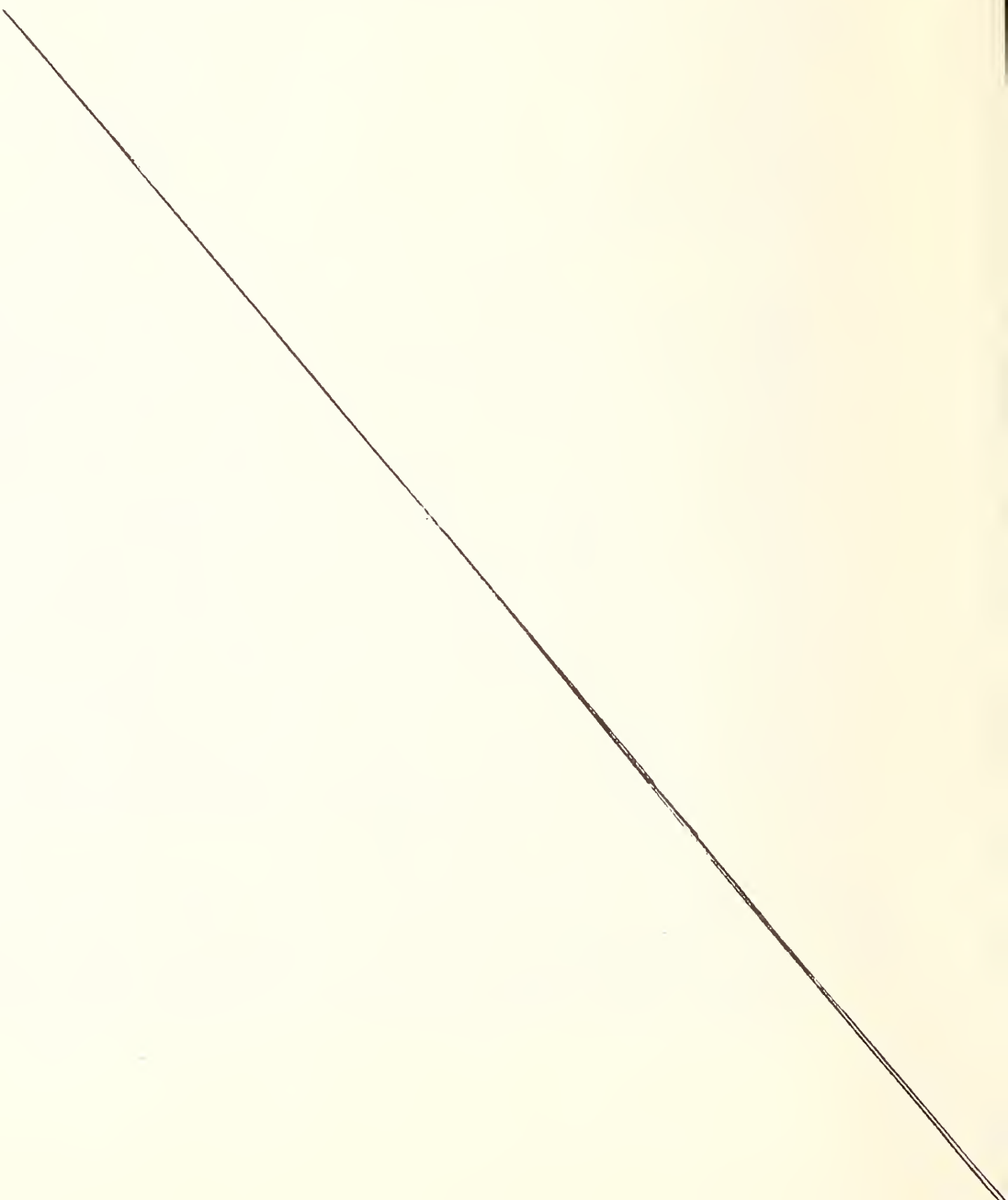
It must be recognized that this data is anecdotal and should itself be subjected to rigorous evaluation. There is a clear need for further data collection and evaluation, both through the existing and proposed Department demonstration activities and possibly through data collection and analysis from existing on-going hospices. We note that current available data seems to suggest that hospice care with a large home care component is one of the promising ways to reduce costs of terminal illness. It would appear further, that the inpatient costs of care at a free standing hospice facility may result in a cost savings over the costs of inpatient care in a general hospital, probably because of hospital overhead from the costs of operating rooms and other specialized technology. At the same time, because of the labor intensive (primarily nurse) situation in a hospice inpatient facility, while it may remain less expensive than a general hospital it will probably be comparable or greater in cost to a skilled nursing facility. 15/

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15/ For example, the \$130 per diem cost at the Washington Home, a certified skilled nursing facility, exceeds the costs of skilled nursing care in the Washington, D.C. area.

### Conclusion

Based upon the Task Force's review of the available information on the hospice movement, it is the Task Force's conclusion that the hospice movement, as a concept for caring for the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for the Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of Federal support.



### III. Department Response

#### A. General

Having concluded that the hospice concept is viable and worthwhile of Federal support, the question becomes-- What should the nature of that support be?

In addressing this question, two considerations should be kept in mind.

First, the hospice movement is already caught up in the Department's health planning and health services delivery activities, which is frequently haphazard or inappropriate. For example, in order to become eligible for Medicare or Medicaid reimbursement, hospices are being forced into organizational and operational modes which may not be desirable <sup>16/</sup> and State comprehensive health plans and certificate of need laws may or may not include hospice activities within their purview, leading to helter skelter growth on the one hand and unenlightened obstruction on the other. Thus, the matter of concern isn't solely what the Federal government will do but also what the Federal government already is doing to or for the hospice movement.

Second, there is considerable concern, both in the government and among the outside groups most knowledgeable about hospice development, that the Federal government, in a rush to embrace hospice, will smother it. It has been correctly pointed out that the movement started without substantial Federal support and thus far appears to be developing in a responsible manner and with desirable diversity and flexibility. Under these circumstances, the Federal role, in the initial stages at least, should be characterized by appropriate modesty and restraint.

Finally, in analyzing the Federal role we have considered hospice care as essentially an element of total health care, albeit a more comprehensive and humanistic way of addressing the problems of the terminally ill, and therefore have viewed it against the backdrop of existing mechanisms in the health care system.

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16/ This issue is discussed in greater detail in the discussion of reimbursement.

## B. Health Planning

Title XV of the Public Health Service Act sets forth a comprehensive scheme for health planning in the United States pursuant to which the Federal government makes grants to participating States 17/ and local health systems agencies (HSA's). Under that scheme, each State, with certain exceptions not relevant here, is divided into health service areas with health systems agencies designated for each area. Each HSA has the responsibility of providing effective health planning for its health service area so that there will be an appropriate development within the area of health services, manpower, and facilities meeting identified health needs and reducing overlapping, duplication, and other inefficiencies. The principal function of the HSA is the development of a statement of goals describing health systems in the area which, when developed will assure that quality health services will be available and accessible in a manner which assures continuity of care, at a reasonable cost, for all residents in the area. The totality of HSA plans within a State combine to make up the State Health Plan, administered by a State Health Planning and Development Agency.

The Department may exercise considerable influence over the development of those plans, as the Secretary is authorized to establish criteria setting forth minimum standards which they must meet.

In addition, under Title XV, each State must adopt certificate of need legislation for the prior review of proposed new institutional health services. Current regulations limit this coverage to hospitals, skilled or intermediate care nursing facilities, kidney disease treatment centers, ambulatory surgical facilities and health maintenance organizations. State certificate of need legislation must meet certain minimum requirements established by the Secretary. Section 1122 of the Social Security Act establishes a parallel mechanism, pursuant to which costs related to proposed capital expenditures by health facilities found by the State to be inconsistent with the State health plan may be excluded from reimbursements to the facility under Title XVIII and Title XIX.

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17/ All 50 States as well as the Virgin Island, Guam, the Trust Territories in the Pacific Islands and American Samoa participate.

The hospice concept has not fit easily into this health Planning scheme.

The logical primary focus of any effort to fit the concept into the health planning system are the HSA's which cover virtually the entire United States and which, as indicated above, have a primary responsibility for planning and monitoring the orderly and effective delivery of health services within their area.

Despite that responsibility, our conversations with hospice organizers and program officials indicates that HSA's are not generally aware of or sensitive to hospice activities, needs, or roles. By and large, the HSA role has been reactive, i.e., responding to an application for a certificate of need or section 1122 review, and even in those cases, reactions have been to view hospice in terms of traditional kinds of facilities such as skilled nursing facilities or home health agencies.

A first possible step in resolving these shortcomings is the development of educational materials to be distributed to all planning agencies explaining the hospice concept. This material could include guidance on the factors to be considered by planning agencies in determining community need for hospice programs. In conjunction with this educational program, the Department could revise its guidelines applicable to the development of health plans to provide that HSA's and State Health Planning and Development Agencies consider the need for comprehensive services to the terminally ill and their families in the development of their respective health plans. While such an approach is probably a desirable one, it is not without drawbacks. Present guidelines do set forth other specific considerations which HSA's and States must take into account in the preparation of their plans. However, those provisions generally deal with discrete or specific kinds of health care e.g., pediatric services and radiation therapy services, rather than a comprehensive package of care for a specified population group such as the terminally ill. A review of the need for hospice services, then, may require a different kind of data collection and analysis and in some cases

may be a significant burden on the fledging HSA's.

The implementation of State certificate of need laws presents a different problem. As previously discussed, Title XV of the Public Health Service Act requires participating States to enact certificate of need programs for the prior review of proposed hospitals, skilled or intermediate care nursing facilities, kidney disease treatment centers, ambulatory surgical centers and health maintenance organizations. To the extent that a proposed hospice would include the establishment of one of those facilities, State review and issuance of a certificate of need would be a prerequisite. However, neither a freestanding hospice nor home health care organization is required by Federal law or regulation to be included in a State certificate of need program.

While States are free to enact broader certificate of need statutes which would include home health agencies and hospices, and in many cases have done so, coverage is sporadic and uncoordinated.

The possible lack of certificate of need coverage for freestanding hospices, and in particular for freestanding inpatient hospice facilities, is for many a source of concern in light of the present problem in many areas of the United States of excess and underutilized bed capacity. Developing hospice programs must however be tailored to a relatively small geographic area in order to be effective in meeting the goals of hospice care in providing daily and extended visits from family and intensive around the clock staffing. It is unlikely that many will exceed 30-40 beds. In the aggregate, therefore, while there doesn't appear to be enough beds at stake to make a substantial difference, the conversion of existing beds rather than the addition of new beds should be encouraged. Another major concern is that conversion of "excess" beds to hospice beds might simply mask the inappropriate maintenance of unneeded beds, and that such conversion, especially of acute care beds in hospitals rather than nursing home

conversion, might also prove to be too costly as well as not a very effective model for provision of hospice services. Because of these variables, which are dependent to a large degree on the existing health care delivery system in the community and the needs in the community, it is important that these facilities not be permitted to spring up without community input through the health planning mechanism; especially if through reducing the barriers to reimbursement for hospice services the creation of new hospice programs of care throughout the country are fostered.

While the section 1122 program will lose any separate meaning once certificate of need laws are in place in all States, the Department may wish to consider the coverage of hospice services within the 1122 regulations so that until that time the component of Medicare and Medicaid reimbursement related to capital costs will be provided only for hospice services given planning agency approval as consistent with State and local health plans. (However, this approach may be of little deterrent value for hospice services not involving significant capital expenditures, e.g., those stressing home health care.) This approach, if it is to be adopted, should be combined with Departmental requirements that these health plans address hospice services in a uniform and consistent manner.

#### C. Direct Operational Support

1. Integration into Existing Health Delivery Systems. Another Federal response might be the award of financial assistance by means of grants or assistance-type contracts. 18/

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18/ Financial assistance as discussed here is distinguished from reimbursement for services rendered, which is addressed in the following section.

(a) Community Health Services. While the Department has no financial assistance program specific to hospice services, there is authority to make grants to organizations such as community health centers, migrant health centers and community mental health centers, each of which is authorized to provide or arrange for the provision of some or all hospice services as part of a more comprehensive package of health services. The most significant of these programs from the point of view of providing hospice services, is the community health centers program which provides primary health care services to population groups which reside in medically underserved areas. A total of 574 community health centers will serve an estimated 4.5 million persons in fiscal year 1978. Each center provides a comprehensive array of family oriented primary health care services such as physician's services, preventive well child services, prenatal and family planning services. It is also within the Secretary's authority to require community health centers to provide certain supplemental health services including "home health services."

There seems to be little question that community health centers could provide or arrange for the performance of the full array of hospice services to terminally ill persons residing in their service area.

However, we have been advised that no community health center is currently doing so.  
19/

Although no data exist to indicate the allocation of dollars among the various services and population groups served by community health centers, our discussion with program officials indicate an emphasis on diagnostic,

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19/ The foregoing discussion is, in general, applicable to community mental health centers, and migrant health centers.

preventive, and curative services to the exclusion of palliative or social services for the terminally ill. While there is no question that a shift in emphasis would diminish services to the current service population, it would seem that a policy weighted so heavily in favor of the "curable" could bear some rethinking. On the other hand, there is simply not enough information available on costs, desirable modes of operation, hospice certification and quality control, or geographic distribution of services to warrant a decision at this time mandating the inclusion of hospice services in the programs of all community health centers.

One way of accumulating the need data would be the use of demonstration grants or contracts. Like the operational assistance discussed above, demonstration grants or contracts are available to finance hospice services.

However, unlike those other authorities, demonstration assistance is limited in time (usually three years or less) and focus (to prove or disprove a stated hypothesis) and does not require large appropriations to support the on-going activities of a national program.

There is ample authority to provide financial assistance by grant or contract to activities designed to demonstrate the efficacy of the hospice concept both medically and fiscally; sections 409 and 410 of the Public Health Service Act authorize cancer demonstration programs 20/ and sections 304 and 305 of the PHS Act authorize programs to demonstrate the

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20/ Under this authority demonstration contracts were awarded to Hospice, Inc. in New Haven, Connecticut, Kaiser Permanente Medical Program, Hillhaven Foundation, Tucson, Arizona, and Riverside Hospital, Boonton, New Jersey.

acceptability, quality, and financing of health services and systems.

Pursuant to these authorities, awards, for example, could be made to functioning community health centers for the purpose of demonstrating the desirability of requiring such centers to deliver some or all hospice services to terminally ill persons residing in their services areas.

(b) Home Health Program. Public Law 94-63 authorizes the Secretary to make demonstration grants to meet the initial costs of (1) establishing and operating public and nonprofit private home health agencies as defined under section 1861(o) of the Social Security Act in areas in which home health services are not otherwise available, and (2) expanding services of existing home health agencies. While this authority is nominally "demonstration," its focus is in financing agency operations. Eligible agencies must be agencies certified as home health agencies under Title XVIII of the Social Security Act. Federal assistance is available only to meet the costs of providing "home health services" as defined in § 1861(m) of the Social Security Act; however, that section does not require that all services provided be reimbursable under Title XVIII. For example section 1861(m) requires that home health services be provided in the patient's home; but there is no express requirement that the patient be home-bound. Should a hospice be certified as a home health agency, it appears that Federal support may be available for a broad range of hospice activities free from some of the artificial restrictions discussed more fully under the reimbursement section. Furthermore, a hospice could obtain support under this program by arranging with a grantee home health agency to provide additional home health services. Because a primary

objective of the hospice movement is to allow the terminally ill person to remain in his or her home amongst friends and relatives as long as possible or until the point of death, support of hospice development through the support of home health agencies - which can be community based, hospital based or based in a public agency - would appear appropriate, and would foster the emphasis on home care with backup inpatient facilities only where, because of a variety of reasons, the patient cannot remain in the home until death. The usefulness of the existing grant authority, however, is limited, first because of the limited appropriation available (5 million dollars) and second, because it is limited to the development of certified home health agencies, which as discussed in the reimbursement section of this Report, is not a totally useful mode for the provision of hospice services.

(c) Health Maintenance Organizations.

Title XIII of the Public Health Service Act authorizes grants and loans to, and Federal qualification of, health maintenance organizations. Each qualified HMO is required to provide each of its members basic health services plus a discretionary package of supplemental health services specifically contracted for. Among the services which must be provided are physicians' services, outpatient services and home health services "... provided at a members home by health care personnel, as prescribed or directed by the responsible physician or other authority designated by the health maintenance organization ...", 42 CFR 110.102(a). However, it has been a consistent construction in the implementation of the program that required basic services are limited to those which are medically necessary. Thus, while it seems clear that most physicians' services, and drugs, would be included in basic health services, it is not at all clear that much of

the counseling and bereavement services could be required to be furnished as a prerequisite to qualification, although these services may well be required to be provided by HMOs as "medical social services" (see 42 CFR §110.108(n), a requirement apart from the basic health services (and medical necessity) requirement.

(d) The National Health Service Corps. Section 333 of the Public Health Service Act authorizes the Secretary to assign health manpower to areas with critical health manpower shortages. The NHSC projects that by 1979 there will be approximately 714 physicians and 230 nurses and physicians' assistants assigned to field sites. These professionals could be assigned the responsibility of providing professional services to supplement those services of a hospice operation in the critical health manpower shortage area to which they have been assigned.

There are also bits and pieces of authority scattered throughout the Department which might be brought to bear on the provision of hospice services. However, given the current lack of data, any comprehensive effort to affect the necessary changes, be they legislative or merely policy, seems premature. A reasonable alternative would be to catalogue all these authorities, note the nature of any changes which might be required, i.e. statutory, regulatory, and then assess how these separate programs might fit within the hospice movement as data begin to develop from the various demonstrations either already underway or imminent.

2. Financial Support for Construction. There appears to be general agreement that new construction authority is not appropriate at this time and serious concern about conversion of beds as discussed previously. It should be noted however that, Title XVI of the Public Health Service Act

provides formula grants, direct loans, and loan guarantees with interest subsidies for the construction, modernization, and conversion of a variety of health care facilities. Such assistance would be available to a hospice to the extent that it provides patient care at least at the skilled nursing level. As a practical matter, however, there is little likelihood of construction financing for hospices through this source, since no additional funds have been appropriated for construction or modernization since FY 1977.

The health services research authority (sections 304-308 of the Public Health Service Act) includes authority for construction of physical plants which (a) provide for new types of architectural or functional configuration for the delivery of health care, or (b) will house a new type of health care delivery, e.g., a hospice program. Not since the early history of this authority has an Administration directed funds toward construction. There has been some Congressional earmarking, however, including the \$1 million appropriated in FY 1978 for the New Haven facility.

Finally, to the extent that a hospice is licensed in a State as a hospital or nursing home, it would be eligible for assistance through the FHA mortgage insurance program, under the National Housing Act. Section 232 relates to nursing homes; section 242 covers hospital mortgages.

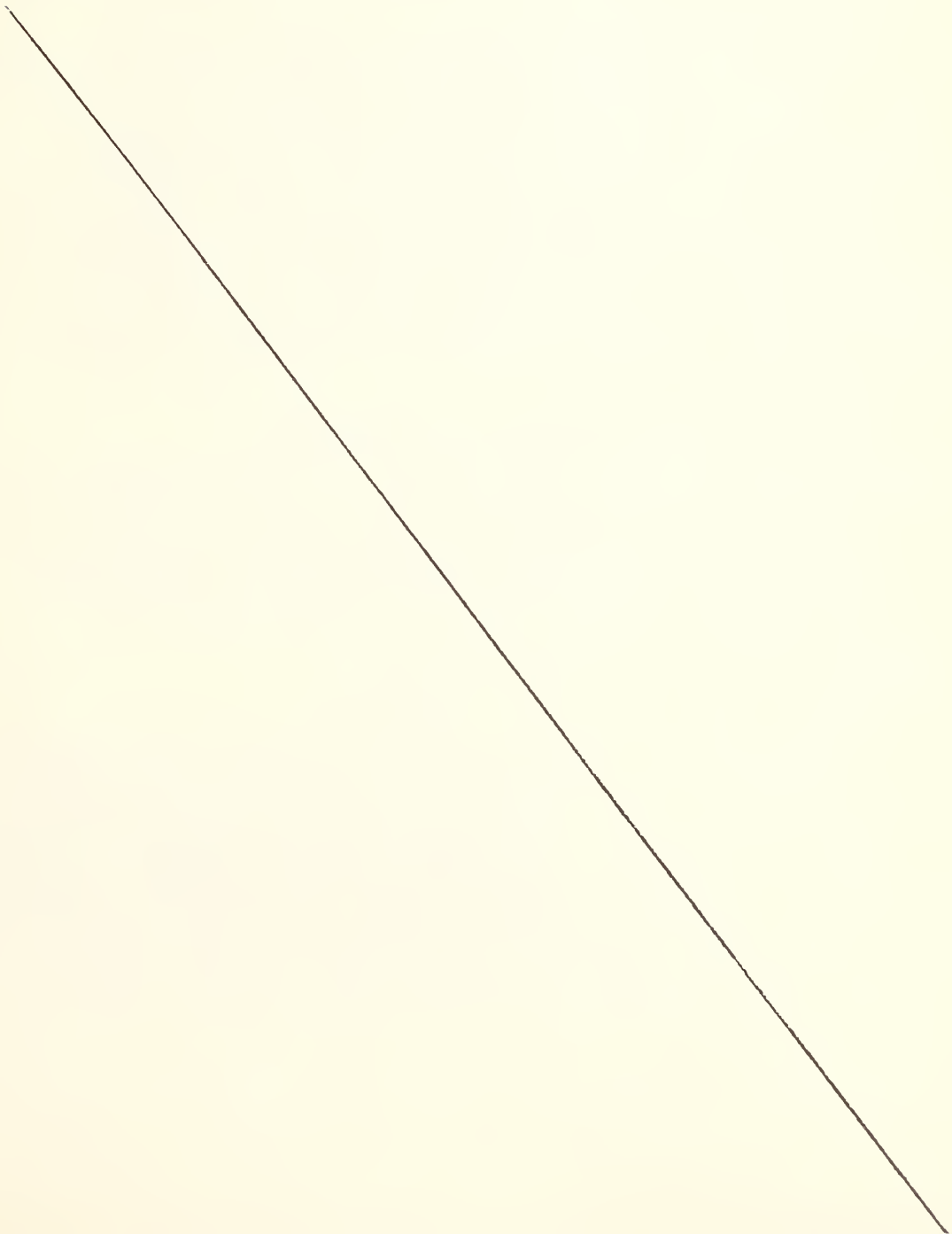
3. Financial support for training. As discussed earlier, an integral part of the hospice program of care is the availability of a multi-disciplinary team to provide care 24 hours a day, seven days a week. What appears to be required is modification of the orientation of traditional professional training to include dealing with the issues surrounding the treatment of the terminally ill so that there will be an available manpower pool to adequately staff hospice programs. The inclusion of this training could be encouraged by guidelines, or required by regulations, in a number of training programs the

Department now supports; for example, programs for training medical students and residents in family medicine (section 786, PHS Act), programs for training of physicians assistants (section 783 of the PHS Act) and programs for nurse training (section 822 of the PHS Act).

To the extent that separate training programs are necessary, Title VII (notably section 788(d), although there is a relatively small authorization for this authority) provides broad authority for health professions training as well as for training programs for social work in health. Title VIII also has ample authority for nurse training, including continuing education. Grants and contracts, where authorized, under these authorities might best be directed toward the creation of model programs. Because of the small number of operating hospices and the fact that most others are still in the planning stages, there is no data on aggregate staffing needs of hospices and the impact this might have on existing manpower supplies. Research in this area would appear necessary before the Department undertakes support of any massive training efforts.

However, there are some indications that the most significant manpower problems are likely to arise in the home care component of hospice programs since home care is not a large portion of the present health care system. The Department does have authority under section 602(b) of Pub.L. 94-63 to make grants for demonstrating the training of home health personnel. For fiscal year 1979 the Department is proposing to accord a preference to applicants who propose to train home health aides. The usefulness of this authority to provide manpower for hospices will be somewhat limited, however, by the adoption of the proposed regulations implementing this authority (43 Fed. Reg. 26534, June 20, 1978) which limit training to personnel of certified home health organizations and organizations that have applied for such certification and persons who show that they are or will be employed by such agencies or organizations.

Finally, training efforts should not be focused solely upon health professionals to be employed by hospices. As indicated earlier, the role of volunteers appears crucial in the success of the hospice movement. Funding of model training programs for volunteers or the facilitation of the sharing of training activities among hospice groups (which seem to be each developing their own programs) might be useful.



D. Reimbursement

1. General. Titles XVIII and XIX of the Social Security Act (Medicare and Medicaid) now reimburse hospices for many of the medical services rendered to the terminally ill. But because of eligibility requirements and other limitations, many of the services rendered are not reimbursable. The Federal response might be to change statutes, regulations, or policies to expand reimbursement to cover more or all hospice services or more or all people in need of services.

This is an issue of critical and immediate concern to the hospice movement. Not only does it have a direct and obvious affect on the ability of hospices to survive financially, but also, to the extent that eligibility of hospices to receive reimbursement under those programs now depends upon their having certain physical characteristics or professional staff, or providing certain services, the pressure to conform simply to qualify for reimbursement exercises a great influence on the shape of the hospice movement in this country.

Medicare and Medicaid

For the purposes of this discussion, we have broken down the issue of Medicare and Medicaid reimbursement into three categories; (1) eligible beneficiaries, (2) covered benefits, and (3) eligible providers of services.

2. Beneficiaries

(a) Medicare

Title XVIII of the Social Security Act, which is in principle and concept an insurance program, has as its principal beneficiaries individuals 65 years of age or older. Two exceptions have been made to that general eligibility requirement; one in favor of persons totally disabled

and one in favor of persons suffering from end stage renal disease. 21/ These categories of individuals are accorded eligibility for the full panoply of Medicare services.

One approach to assisting the hospice movement that readily suggests itself is the creation of a new category of beneficiary--the "terminally ill" (and the provision of the full or a more limited package of Medicare services and "hospice" services to this group.) The exceptions for the totally disabled and for the victims of end stage renal disease are precedents for such a move. Another approach would be to expand the definition of the totally disabled to include the terminally ill and eliminating the 24 month waiting period requirement for this group. Although data on the number of terminally ill who are under 65 are not readily available, Hospice, Inc., New Haven estimates that 56% of its patients are under 65.

On the other hand, the potential exists for that category to become very large, depending upon how one defines "terminally ill." The very young, including infants, may be terminally ill, and people with diabetes, emphysema, advanced heart disease, and a myriad of diseases other than cancer also could be

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21/ Neither of these exceptions provides useful entitlements for hospice patients. To qualify as disabled a person must have been entitled to social security disability benefits for 24 consecutive months. As indicated earlier, the average life expectancy of a hospice patient is 3 to 4 months. Even assuming that a hospice patient also suffers from end stage renal disease, the average 3 month waiting period for eligibility in that regard would exclude the greater part of the patients' remaining life.

classified as being terminally ill. If Federal reimbursement becomes available great pressure will be created to add to the ranks of the eligible. 22/

Furthermore, the decision to single out the terminally ill for favored treatment over all other groups or health needs is one which deserves more debate and justification than currently has taken place.

(b) Medicaid

The Medicaid program, in contrast to Medicare, is not an insurance program, but rather a program based upon need. Furthermore, unlike the Medicare program, Medicaid is a residual program, i.e., it pays a cost only if some other payor is not available. Consequently, if the definition of totally disabled is expanded to include the terminally ill (without an advance waiting period) or if a new beneficiary group comprising the terminally ill is added to Medicare, nothing would be gained by modifying the Medicaid program. (Any Medicaid terminally ill individual would be covered under the expanded Medicare program.)

The concept of expanding the beneficiaries of Medicaid to include the terminally ill is foreign to the structure of the Medicaid program and would be more of a conceptual departure from the structure than would be the addition of the terminally ill to Medicare. Medicaid eligibility is primarily related to eligibility of individuals for cash assistance. (AFDC, SSI, state supplementary payments)

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22/ Presumably, any statutory amendments to bring the "terminally ill" under Medicare would retain the sort of insured status requirement applicable to the ESRD program. See §226A(a)(1)(A) of the Social Security Act. Thus, the concept of Medicare as an "earned right" will have been preserved. On the other hand, not all the "terminally ill" will qualify under such a program.

States may also elect to cover the medically needy (individuals who would otherwise be eligible for cash assistance--i.e., from a broken family or the aged, blind, or disabled--except for having too much income or resources). These individuals are permitted to establish Medicaid eligibility after "spending down" to the State-set income level any excess income by incurring medical expenses in the amount of the excess. It is only in the context of the State-option medically needy program that Medicaid eligibility is set somewhat independently from receipt of cash assistance. However, even under the medically needy program, the factors other than income, such as dependency, age, disability, and blindness are set with reference to the cash assistance programs (AFDC, SSI or its 1972 predecessors).

It is likely that the needy "terminally ill" are already Medicaid eligibles and that no adjustment in eligibility is necessary for them. For example, individuals who meet SSI income criteria and are terminally ill would probably qualify under the SSI definition of disabled, §1614(a)(3) of the Act:

An individual shall be considered to be disabled . . . if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death . . . .

The applicable regulations implementing this provision are found at 20 C.F.R. §416.901 et seq. Thus, for those states which use SSI as a basis for Medicaid eligibility the terminally ill--who are

poor--would be eligible. (Even those states which use more restrictive eligibility criteria contained in their 1972 state plans would be bound by the SSI definition of disability, since §1902(f) of the Act defines a disabled individual as one disabled "within the meaning of title XVI.")

### 3. Benefits

It is in the area of eligible benefits that the anomalies of using a highly structured system focusing on diagnosis and therapeutic medical care to reimburse for hospice services are most pronounced. The anomaly is exacerbated by the tendency to qualify coverage depending upon the facility or context within which the service is being performed. For example, under Medicare, if a patient is homebound, reimbursement is available to home health agencies for home health care. If the patient is ambulatory, outpatient hospital care under Medicare is available. If the patient requires confinement in a facility, Medicare reimburses either for inpatient hospital or skilled nursing facility (SNF) care, depending upon the level of care that the patient requires. 23/ However, some patients fall between these categories. Medicare does not currently reimburse for home health services if a patient is not home bound, i.e., completely confined to the home and not able to get out to get the mail or go shopping, etc. As indicated earlier, a principal goal of the hospice concept is to keep the patient mobile and active i.e., not homebound within the current strict Medicare definition, as long as possible.

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23/ While at one time the emphasis on rehabilitation potential led to a Department interpretation that a terminal patient could not, by definition, qualify for skilled services, this later was clarified. While no systematic documentation exists for the concern that Medicare intermediaries continue to deny claims for this reason, it might be desirable to send out a transmittal reminding intermediaries of the policy embodied in 42 C.F.R. §405.127(b)(2) in order to assure compliance. That section specifically states "For example, even though no potential for rehabilitation exists, a terminally ill cancer patient may require skilled services as defined in the following paragraphs of this section."

We believe, however, that through changes in the existing regulations the Department can lower the obstacle posed by the statutorily imposed "home bound" requirement. Section 1835(a)(2)(A) of the Act requires that a physician certify that home health services are or were "required because the individual was or is confined to his home." Although the Secretary may not eliminate this restriction without securing a statutory change, he could define the concept of "confined to his home" to presumptively include any individual who is diagnosed as "terminally ill."

Nor will Medicare pay for custodial care or services not deemed medically necessary. Consequently, the hospice concept does not fit the conceptual categories of the Medicare program since it is a comprehensive approach to the care of the terminally ill which transcends the normal Medicare provider and service classifications.

In addition to these conceptual limitations, Medicare benefits are encumbered by many rules and classifications which are peculiar to standard medical treatment modes, but which do not fit a comprehensive and flexible approach to the care of the terminally ill. For example, home health aides who do not provide a "skilled" service in traditional Medicare terms may not be reimbursed 24/; physical therapy in the

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24/ While it is correct that present Medicare policy does not authorize the coverage of the services of home health aides who do not provide skilled services, the statutory payment authority is arguably more liberal. Section 1861(m) defines covered home health services as including:

"(4) to the extent permitted in regulations, part-time or intermittent services of a home health aide."

While any liberalization of coverage would have to consistent with the "medical necessity requirement" (Section 1862(a)(1)) and the "level of care" requirements (e.g., Sections 1814(A)(2)(D), 1835(a)(2)(A), 1862(a)(9)), there does appear to be discretion to expand this benefit. The traditional argument against doing so has been that the scarce health benefit dollar should be devoted to skilled health care, rather than to chore-workers and other unskilled services.

home must be restorative rather than palliative and the cost of drugs will not be reimbursable if administered in a home care setting. 25/ Home health benefits are payable under Part A of Medicare only if there has been a prior qualifying stay in a hospital or skilled nursing facility. (See §1861(m).) This limitation does not apply to home health benefits under Part B.

One other major area of hospice services is ineligible for reimbursement - counseling and bereavement services rendered to the family of the terminally ill patient. 26/ Title XVIII

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- 25/ Other limitations which could bear review are: (1) eligibility in a SNF requires a prior 3 day hospital stay, §1861(i), (2) admission must be within 14 days of discharge or readmission to a hospital is required, §1861(i), with certain exceptions listed in that section, also see 42 C.F.R. §405.120(d), (3) if a patient requires hospitalization but refuses, he or she becomes ineligible for home health benefits (Home Health Agency Manual (HIM-11) §204.1). Hospice representatives also advise us that cost ceilings do not account for the longer and more frequent nursing visits necessary when caring for the terminally ill nor does Medicare reimburse for home aides in many needed nontreatment capacities. (There are no "cost ceilings" applicable to home health agencies in the sense that term is applied on a mandatory basis to hospitals (See 42 C.F.R. §405.460). However, intermediaries do use cost screens and similar devices as guidelines in reviewing provider cost reports.)
- 26/ Title XX of the Act provides a possible alternative for reimbursing the counseling portions of the hospice approach. Under title XX, there are five goals listed (§2001) for which states may use their social services funds and receive Federal matching. Among these goals are achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency, . . . achieving or maintaining self-sufficiency, including reduction or prevention of dependency, . . . [and] preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care." These goals are broad ones and would seem to permit states to include bereavement counseling within their Title XX services plan (if they so choose).

covers services only when furnished to a beneficiary, not members of his family. Unfortunately, there is not yet any clear delineation of what counseling and bereavement services are or should be. For example, should they include full psychiatric services, needed rest and recreation, or religious support and counseling? Until there has been a delineation of what the needed services should be, no assessment can be made of whether they should be covered by the Medicare statute, or of what the cost to the Medicare system would be.

The Medicaid program, like the Medicare program, does not currently list hospice services as one which may be covered, nor does the Medicaid program specify hospices as a type of provider of services. At present a hospice could be reimbursed under Medicaid only to the extent that it provides any of the services listed in the Act which are covered by the State's Medical assistance plan. This could involve inpatient hospital services (§1905(a)(1)), outpatient hospital services (§1905(a)(2)), rural health clinic services and any other ambulatory services which are offered by a rural health clinic and which are included in the state plan (§1905(a)(2)), skilled nursing facility services (§1905(a)(4)(A)), and services furnished by a physician (§1905(a)(5)), which all states must cover in their Medicaid plans. Optional (with the State) benefits which now would reimburse for some of the services provided under the hospice concept are: medical care . . . furnished by licensed practitioners within the scope of their practice as defined by State law

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Continued

26/ Under title XX, states are subject to a ceiling on Federal financial participation (§2002(a)(2)(A)). Receipt of title XX services are also subject to a financial needs test (§§2002(a)(5) and (6)). However, in the context of discussing options for a Federal response to the hospice concept, the potential of title XX should be considered.

(§1905(a)(6)), home health care services (§1905(a)(7)), clinic services (§1905(a)(9)), prescribed drugs (§1905(a)(12)), other rehabilitative services 27/ (§1905(a)(13)), and intermediate care facility services (1905(a)(15))28/.

The list of services which states may include in their Medicaid plans also includes a general provision (§1905(a)(17)): "any other medical care, and any other type of remedial care recognized under State law, specified by the Secretary . . . ." "Hospice services" have not been specified by the Secretary under the regulations at 42 C.F.R. §449.10(b)(17) and thus cannot be included by the State under §1905(a)(17). However, the Secretary could, by regulation, include "hospice services" under §1905(a)(17), if he could define them.

If the Department were to change the regulations governing §1905(a)(17) to include "hospice services" and either specify what these services include or leave this issue to the states which elect to include hospice services in their Medicaid plans, it would constitute a recognition by the Department that hospices are, at least for Medicaid reimbursement, a legitimate recipient of funds. An alternative to changing the regulation to specifically authorize states to include hospices in their Medicaid plans would be to seek a statutory change to specify hospice services as one of the §1905(a) services, either a mandatory or optional one.

The Department has a broad range of options in seeking to change the Medicaid program to accommodate the hospice concept. One approach could

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27/ The Regulations at 42 C.F.R. §449.10(b)(13)(n) define rehabilitative services as including "any medical remedial items or services prescribed for a patient by his physician or licensed practitioner of the healing arts, within the scope of his practice as defined by State law, for the purpose of maximum reduction of physical or mental disability and restoration of the patient to his best possible functional level". It could be argued that with respect to the terminally ill, hospice attempts to restore the patient to his best possible functional level.

28/ Under the list of services contained in §1905(a), bereavement counseling portions of the hospice approach could be reimbursed if the states include such counseling as part of any of the medical services (contained in that section) covered in their state plans.

be to make hospice services part of the mandatory services. (Legislation would be need for such a change.) Another approach, discussed above, would be to amend the regulations to provide, under §1905(a)(17) that hospice services (therapeutic or palliative) are an optional reimbursable services.

#### 4. Providers

##### (a) Medicare

Hospices are not, in and of themselves, an eligible category of providers of services under Title XVIII. <sup>29/</sup> As a result, hospice services may be reimbursed only to the extent that they are rendered in connection with a hospital, skilled nursing facility (SNF), or home health agency participating in the Medicare program. Because of the emphasis under Title XVIII on curative medical services those classifications are often inappropriate. For example, a home health agency must be primarily engaged in providing skilled nursing services and other therapeutic services (section 1861(o) of the Social Security Act). Similarly, a skilled nursing facility must develop an extensive capacity to perform diagnostic tests and therapeutic care (section 1861(j) of the Social Security Act and 42 C.F.R. §405.1101 et seq.) In both cases, requirements of diagnostic and therapeutic services may be anomolous to individual hospice operations and at the very least be significantly restrictive of the flexibility which is so desirable at this state of the hospice movement.

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<sup>29/</sup> The term "provider" (for Medicare) is defined in §1861(u) of the Act. Only providers may be reimbursed under the Part A (Hospital Insurance Benefits for the Aged and Disabled) program of Medicare.

In our later review of hospice standards, we discuss the establishment of minimum criteria for, or a working definition of, an operational hospice. That definition might be used as the basis for the creation of a new category of provider--the hospice--thereby avoiding the anomalies of present classifications. The principal effect of developing a new, flexible category of provider for hospices should be the avoidance of artificial organizational machinations. But unless some of the other statutory requirements are changed, such as the prohibition on custodial care contained in §1862(a)(9), the creation of a new provider category of "hospice" would be of limited value. Without changes in the benefits which Medicare covers, the "hospice" provider will not be able to provide any services or care under Medicare which are not presently covered under that program. However, if changes are made which would provide for coverage of hospice services by Medicare, it would be far more advantageous to include "hospice" as a category of provider. Alternatively, the hospice benefit could be confined to Part B, as in the case of rural health clinic services.

(b) Medicaid

Under the Medicaid program, the concept of provider of services is essentially irrelevant to whether services are covered under the State's Medicaid program or to whether particular groups of individuals will be eligible to receive these services. This is in contrast to the Medicare statutory framework in which the "provider" assumes a significant role. Creating a category of provider in Medicaid will not add to the population of eligibles who would receive the particular services. Similarly, creating a new category of provider will not add to the types of services which may be offered by a State under its Medicaid program.

5. Demonstration authorities.

In our discussion of financial assistance for hospice services, we pointed out that demonstration authority existed to perform many of the hospice services on a limited basis so as to prove or disprove certain hypotheses before committing substantial resources. The same is true in the case of reimbursement for hospice services. Section 222(a) of Pub. L. 92-603 and Section 402 of the Social Security Amendments of 1967, P.L. 90-248, as amended by § 222(b) of the Social Security Amendments of 1972, P.L. 92-603, 42 U.S.C. § 1395b-1, provide extensive authority to fund projects free of some or all of the restrictions outlined above without seeking amendatory legislation.

Thus, a number of alternatives present themselves; (1) seek legislative changes to remove barriers to reimbursement for hospice services, (2) do nothing legislatively but continue to fund demonstration projects designed to test the fiscal and other feasibility of providing a full range of hospice activities, or (3) combine these two approaches by seeking legislation in clear cases and awarding demonstration grants or contracts in others.

In approaching this problem it must be kept in mind that very little hard data exist with respect to hospice activities. This is due in part to the fact that it is only recently emerging as a viable concept and in part due to the fact that its services have often been inextricably interwoven with standard health care procedures.

In view of the variety of forms that hospices take, as discussed in this paper, and in view of the continuing evolution of the hospice concept, it would be premature to attempt to define a hospice paradigm by legislation. Unless the provision would leave the definition entirely within the discretion of the Secretary's regulations, it would be bound to exclude some entities which ought to be included. It would stifle evolution because hospices would conform to the requirements for reimbursement. Further, such a definition would accomplish nothing unless it would also define a new category of benefits-hospice services.

Similarly, while a number of the myriad limitations on reimbursement for benefits may seem appropriate for legislative relaxation, caution should be exercised. Ability to effect desirable legislative changes will be limited by fiscal considerations. A legislative relaxation of one limitation may, because of the ultimate cost, preclude two or three other changes which subsequent experience demonstrates would have a significantly more beneficial impact on the hospice movement.

The most significant move at this time would be experimentation to determine the potential effect of hospice services on Medicare and Medicaid reimbursement. This approach would on a time limited basis, at least, extend benefits to those who need it, would permit the various models of hospices to continue their evolution without artificial influences, and would produce data and experience which would enable the Congress to make the ultimate policy choices on a deliberate, informed basis.

As discussed in the context of Medicare, the Department has demonstration authority available to conduct experiments with the hospice concept. Although fragmented into specific categories, section 402(a) of the Social Security Amendments of 1967 (as amended by section 222(b) of the Social Security Amendments of 1972) provides some opportunity for these experiments and demonstrations in both Medicare and Medicaid. Unfortunately, in order to conduct an experiment under that authority (which was designed primarily for experimentation with alternate forms of reimbursement), the experiment must either involve an "alternative method of payment or reimbursement" (§ 402(a)(1)(A)) or the services to be provided must be furnished by organizations and institutions which have the capability of providing "comprehensive health care services, ambulatory health care services, or institutional services which may substitute, at lower cost, for hospital care" (§ 402(a)(1)(B)). These restrictive categories for the demonstration authority complicate the designing of demonstration projects in the hospice area. Medicaid has demonstration authority available under § 1115(a) of the Social Security Act which is not as restricted as the

§ 402 authority discussed above. However, since most demonstrations (if not all) in the hospice area will involve Medicare, section 1115 authority (which does not apply to Medicare) is not useful.

E. Non-financial Assistance. 29/ As pointed out throughout this Report, the impetus for the growth and development of the hospice movement has thus far clearly come from the private sector. While many organizations contacted throughout the preparation of this Report see a definite role to be played by the Department, they are virtually unanimous in stressing the very significant role that the private sector should continue to play in the development of the hospice movement. The Department can nonetheless occupy a leadership position in fostering this development.

Basic to the exercise of leadership would be an "endorsement" of the hospice concept as a legitimate, humane, worthwhile, and viable concept of caring for the terminally ill and their families.

Continued impetus could be fostered in a variety of ways:

--As a concept of medical care, it is clear that the acceptance and growth of the hospice movement is inextricably interwoven with the attitudes of personnel in the health professions. This is clear from the need to have physicians, nurses, pharmacists, psychiatrists, dietitians, to name a few, all actively involved in the multi-disciplinary hospice team in order to have high quality hospice care available. Some professional associations, such as the American Medical Association and the American Nurses Association, have taken positions favorable to the hospice concept. There remains a need however to involve these and other professional associations, especially local professional societies, actively in the development of the hospice concept, particularly in educating their members through continuing education activities so that local communities can develop comprehensive and high

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29/ The Task Force recognizes that the initiatives discussed in this portion of the Report are not without cost. However, they are not what are commonly included within the term financial assistance - e.g., grants and assistance type contracts.

quality hospice programs. This also would include representatives of the institutional providers - hospitals, skilled nursing homes, etc. in order to try and foster an understanding of hospice concepts and their integration into the existing health care delivery system.

To this end the Department could sponsor a meeting of representatives of professional associations to focus on the hospice concept itself and on the specific role of these professional associations.

-- Private employers, major employee groups and private insurers play a major role in the nation's health policy. The active and ongoing participation of these groups in the development of an approach to the hospice concept is critical to its appropriate integration into the country's health care system. A meeting with the insurers, for example, would explore their perceptions of hospice and their experiences in approving claims for such services which could be very valuable in shaping the Department's approach.

-- As the hospice movement develops the Department will become the focus for requests for information concerning the hospice movement. The development of a capacity to respond to these requests with detailed information on the hospice concept and the hospice movement will be necessary if knowledge about the hospice concept of care is to be available nationwide. The Department might also organize workshops through the Regional Offices, to assist hospice practitioners and interested groups in the areas of program development, management, space design, staffing and funding.

-- At the same time as responding to requests, a planned program by the Department of dissemination of a series of information packages (written as well as through audio-visual approaches) on the hospice concept of care for the terminally ill and their families could itself serve as the impetus for a community to begin to think about the appropriateness of the care presently being given in that community for the terminally ill.

#### IV Other Federal Activities

As indicated in other portions of this Report, the hospice movement started and is spreading rapidly without any significant Federal involvement or support. As Federal agencies do start responding to the needs that form the basis for the goals of the hospice movement it is important that these responses be coordinated as well as consistent. Moreover, the Department, as the primary Federal agency responsible for the development of the nation's health policy can act in a leadership capacity in bring together various governmental agencies whose actions impact on the development and availability of a hospice program of care.

The Task Force's initial contacts with the Veterans Administration indicated that the Veteran's Administration has activities underway supportive of the hospice concept. At the Wadsworth Veterans Administration Center in Los Angeles, California, a palliative treatment project program is being established with a fifteen bed unit in the acute care hospital setting serving as support to a home program of probably 25-30 patients. The estimated costs of the program is approximately one half million dollars. The evaluation protocol for the program will focus on approximately 25 areas of concern and provide data on a comparison group of patients not receiving hospice care in the hospital including: whether symptoms considered preventable (for example, bed sores) occur less, what conditions arise because of deteriorating conditions considered non-preventable and beyond control, and how survivors are affected during the bereavement period. The VA anticipates serving a mix of patients with terminal illnesses including obstructive chronic pulmonary disease, renal failure, and heart failure. The program will open in October and entails intensive training for staff. A few medical schools in the area will offer one month electives in the program. The Wadsworth Center program should provide data and experience which will not necessarily be gathered from the NCI or HCFA demonstrations. In general, the Veteran's Administration appears interested in developing a coordinated Federal role in the development of the hospice movement.

Contact with the Department of Defense indicated that as of this date there has been no demand from military enrollees or beneficiaries to initiate coverage for hospice care, so no Department of Defense activity in this area is envisioned for at least the next year. The Department of Defense does however participate as a member of the Inter-agency Committee on New Therapies for Pain and Discomfort.

Contacts with personnel at ACTION indicates that they are already involved in activities supportive of the hospice movement under the authority of the National Older Americans Volunteers Program and that they are anxious to increase their activities. Under the Retired Senior Volunteer Program for example, volunteers are presently working in both a home care hospice program in Ojai, California and in the Hillhaven Hospice in Tucson, Arizona.

#### V. Quality Control

1. Standards for Hospice Programs. At the present time there are no established standards for "certification" of hospice programs of care either for purposes of defining appropriate hospice services or judging the quality of those services. There is consensus, however, both in and out of government, that because of the increasing interest in establishing hospice programs in this country, we must strive to establish such standards promptly to avoid the problems prevalent in the nursing home industry. If hospice programs, per se, become a reimbursable service under Medicaid and Medicaid, a proliferation of hospices can be anticipated thus increasing the need for some means of quality control. There is particular concern that the growth of hospice programs creates an environment for profiteering and that instead of the creation of a caring community to deal with the terminally ill, there may be the creation of "death houses". Finally because of these concerns, many individuals who have been contacted by the Task Force during the preparation of this Report have stressed the need for the development of standards for hospice programs regardless of whether the Federal Government begins to reimburse for hospice services or undertakes any other type of financial support for the creation of hospice programs.

While at this time the Department has not initiated any activities toward the creation of special hospice standards, 30/ there are a number of activities currently underway outside the Department. On the State government level we have identified activities in Arizona, Connecticut, Florida, Virginia, and Texas, directed toward the creation of specialized licensure and certification of hospice services.

In the private sector the major activity now underway is the development of hospice standards by the Accreditation and Standards Committee of the National Hospice Organization. Once developed, these standards are expected to form the basis for review by the National Hospice Organization; only those programs which meet these standards would be certified by the National Hospice Organization as a "hospice" and they will also be used by the National Hospice Organization for ongoing evaluation of hospice programs. Following the adoption of these standards, we understand that the National Hospice Organization intends to develop guidelines which further implement the standards as well as to develop an accreditation manual. Although these standards are still under development they are intended to cover issues of staffing, availability of care, administrative structure, training, and medical records. Activity is also underway in professional medical associations which are starting to endorse the hospice concept. The California Medical Association, for example, has begun to develop standards for hospice care.

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30/ Of course the hospice programs currently reimbursed under Medicare are required to meet the existing certification standards for hospitals, skilled nursing facilities, intermediate care facilities or home health agencies, as appropriate. For example, the Hillhaven Hospice in Tucson, Arizona is a certified skilled nursing facility and Hospice, Inc., New Haven is a certified home health agency.

The most obvious way for the Federal government to assure that there are standards for hospice care would be to develop standards and certification procedures itself for programs wishing to be deemed a "certified hospice". The proposed HCFA demonstration projects discussed earlier are to be aimed, in part, at developing appropriate certification standards. This approach is, of course, the one used in Medicare and Medicaid for hospitals, home health agencies, etc., and would be tied to the receipt of Federal assistance.

An alternative approach to Federal certification would be the use of a private, broadly based national organization for that purpose. The Federal government could stimulate the development of such an organization by means of grant or contract support 31/ or by providing technical assistance. Furthermore, that organization could be invested with leverage by recognizing it as the certifying agent for purposes of eligibility under Medicare and Medicaid programs. The use of such private organizations has a long tradition in the Department, most notably in the education field, as well as within the private sector in the health field, e.g. the Joint Commission on Accreditation of Hospitals. 32/ The receipt of this certification would be a prerequisite to eligibility for Federal financial assistance, but as indicated previously, even if no Federal assistance is provided it is important for there to be a mechanism of review and evaluation of programs of care so that individuals in a community that want to avail themselves of a hospice program of care can assure themselves that an organization has the capability of meeting the goals of hospice care.

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31/ See, for example, sections 304, 305 of the PHS Act.

32/ While the recent "Report to the Congress on Survey of JCAH Accredited Hospitals" discloses significant gaps in the review conducted by JCAH, those gaps are principally in the area of review of fire safety standards, an area in which JCAH inspectors, mostly health professionals, have little expertise. Naturally, in identifying an organization to review hospice qualification, attention would have to be given to the overall expertise of such an organization.

2. Utilization Review. At the present time there is no Federally mandated peer review requirement applicable to hospices, per se. However, where hospice services are provided in certified hospitals, skilled nursing homes, and intermediate care facilities, the peer review requirements applicable to these facilities apply. Where hospice services are provided by a certified home health agency, utilization review is conducted by the intermediaries. The appropriateness of using these review mechanisms for hospice services already covered by reimbursement needs to be reassessed in terms of the unique nature of the hospice concept of care, focusing in particular on the psychological and physical aspects of care of the terminally ill and on the patient and family as the unit of care. For example, nursing staff of a hospice program provide what might be considered non-"medically necessary" services which nonetheless may be very necessary to meet the goals of hospice care and utilization review mechanisms should take this into account in evaluating nursing charges. Similarly, some home care hospice programs have experienced difficulty in getting adequate reimbursement for home care visits of nursing personnel because of the increased time this personnel spends at each visit compared to the norm, which extra time may be accounted for by performance of psychological support activities and family counseling by the nursing personnel. Further, in light of the extensive use of a multidisciplinary team in providing hospice care and the fact that the differences in the roles performed by members of the team are not as distinct as in the traditional medical model, there may be the need for more professional disciplines to be involved in the review system for hospice care.

3. Fraud and Abuse. Task Force is acutely aware of the need to build into any system of Federal support a substantial oversight and monitoring component, not only to assure that the financial interests of the Federal government have been

protected, but also to assure that the public is directly protected against the charlatan. This latter element is especially important since hospice programs are dealing with individuals in emotionally charged situations when they are most vulnerable to exploitation.

However, until the Department determines what courses it wishes to pursue in support of hospice, what modes of care it may favor, and who the beneficiaries and providers may be, it is premature to discuss detailed plans for preventing fraud and abuse. Federal programs of financial assistance and reimbursement offer opportunities for fraud, abuse and waste to providers or grantees and contractors as well as to patients. If a grant program to support the planning, development and operation of hospice programs is pursued, for example, it may be that the traditional audit of the grant program (carefully carried out) together with limitations on eligibility and use of funds may be sufficient. Where an approach of funding patient care through Medicare and Medicaid reimbursement is pursued on the other hand, this would, judging from past experience be a most fertile environment for a variety of fraudulent and abusive practices to occur and may require special additional safeguards tailored to the peculiar opportunities for abuse in a system where one would not have the precedent of standards of medical necessity. In any event the potential for fraud and abuse in any course of action and the available means to minimize its impact should be an integral part of the Department's decision making process on the wisdom of undertaking a particular activity. Each different proposed Department activity - grants, certification, reimbursements, demonstrations, - brings with it its own peculiar fraud and abuse problems. It may be that the potential for fraud and abuse in a certain course of action is so great and the existing means of combating it so ineffective that the Department should decide not to undertake that approach until a satisfactory mechanism for control of fraud and abuse is already in place. These decisions will need to be made as the Department's plan of action takes shape. Certainly the awarding of demonstration contracts and grants should take these needs into account.





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